Eleventh Meeting of the Washington Group on Disability Statistics

Development of a disability question set suitable for children.

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First of all many thanks to all the group . . .

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Points of reference for the group

The Convention on the Rights of the Child (Unicef, 1989) was the first explicit provision relating to the rights of children with disabilities.

It included a prohibition against discrimination on the grounds of disability (art. 2), and obligations to provide services for children with disabilities, in order to enable them to achieve the fullest possible social integration (art. 23).

The Convention on the Rights of Persons with Disabilities (UN, 2006) further strengthened the rights of children with disabilities .

Article 1: Definition of disability

- A long-term physical, mental, intellectual or sensory impairments which and their interaction with various environmental barriers

Article 7: Children with Disabilities

- Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

Article 31 - Statistics and data collection

- Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention

Main building blocks

Purpose: to develop a question set to investigate the opportunities of participation of children with disabilities compared with same age children and taking account of the definition of disability set out in the UN convention.

The articles from UN Convention mirror those that support the work the WG accomplished with the short set of questions for census "identifying equalization of opportunities" as the purpose for collecting information on disability.

The same for children: Identify the population at risk of participation restriction or social exclusion.

Consistent with the activities of the Washington Group (WG) and based on the consensus from the last meeting, the ICF-CY is the conceptual framework to select the relevant domains.

The work done

Documentation relating to the measurement of childhood disability has been collected and analysed, especially questionnaires of surveys on children already conducted in several countries.

All questions related to children disabilities were mapped onto the ICF-CY Check list to see which domains had been covered in at least one of the surveys.

The ICF-CY Check List has been sent to all members of the group asking them to rate each ICF-CY domain on 6 criteria (Relevance, Accuracy, Reliability, Coherence and comparability, Clarity, Validity)

? for the purpose of creating a WG set of questions for children. Each criteria could be given a score from 1 to 5 (were 1 is the minimum and 5 is the maximum).

Annex 1

Selected Domains

The workgroup selected the following ICF-CY domains:

seeing
hearing
mobility
communication
learning and applying knowledge
relationships
playing

Some of the selected domains may require more than one question.

The domain of self care will be considered in a second stage of the work.

A review of all the questions already used in surveys on the selected domains was done.

Annex 2

Some guiding principles (1)

1) Need to use a **biosocial model** to produce a set of questions that is going to be current, relevant and sustainable

2) the distribution of types of disability are different for children compared with adults, as reported in publications from studies at the national and international level. In children the main disabilities by far are related to intellectual functioning, affect and behaviour.

3) the reference age for the new set of questions is 0-17 years, as stated in the ICF-CY.

The group is also aware that children are constantly developing and in transition - from infancy to childhood, from childhood to adolescence and from adolescence to adulthood.

For this reason the selection of the activity could change from one stage of life to another as well as the wording should be adapted to each specific age considered.

Some guiding principles (2)

4) the responses will be elicited from proxies, at least for the moment. There are studies indicating differences in the answers provided by parents and children (O Dickinson H., 2007) to the same set of questions. Frequently, children and parents have a different perception of reality. Nevertheless, sets of questions addressed directly to the children, Activities Scale for Kids (Young, 2002), are rare.

5) the questions should refers to "life situations" ideally applicable to children in different countries in order to facilitate international comparability. Therefore the group agreed to include examples in the wording, if it needed, giving the possibility to each country to use culturally equivalent examples.

Questions

The questions presented should be considered as an initial proposal open to suggestions and comments.

The selection of questions, that should be considered an initial proposal, was done by:
- using, wherever possible, the questions that have already been tested and adopted by the WG.
- avoiding questions with a medical approach;
- using, when available, questions already age-specific were proposed while in other cases they were adjusted for specific ages.

The wording of the questions and the answer categories were changed to fit WG questions design in order to harmonize the set of questions and to obtain a graduation of difficulty.

Questions has been brought to the attention of an Italian paediatrician who suggested, in some cases, different age range that have been reported in parentheses.

Questions (1)

SEEING (WG)

Children aged 0<=x<=17 years

1) Does [he/she] have difficulty <u>seeing</u> [even when wearing his/her glasses]? Would you say… [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all/unable
7) Don't know
9) Refused

HEARING (WG)

Children aged 0<=x<=17 years

2) Does [he/she] have difficulty <u>hearing</u> [even when using a hearing aid(s)]? Would you say… [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Questions (2)

MOBILITY

Children aged 6 months<=x<1 year (10 months<=x<=15 months) (GB)
3) Compared with children of the same age does [he/she] have difficulty <u>standing holding on to furniture</u>? Would you say… [*Read response categories*]

Children aged 1 year<=x<2 years (15 months<=x<=24 months) (GB)
4) Compared with children of the same age does [he/she] have difficulty <u>walking few steps without help or without holding on to something</u>? Would you say….[*Read response categories*]

Children aged 2 years<=x<3 years (GB)
5) Compared with children of the same age does [he/she] have difficulty <u>walking on a flat firm surface at least 50 meters without help from someone</u>? Would you say…..[*Read response categories*]

Children aged 3 years<=x<5 years (GB)
6) Compared with children of the same age does [he/she] have difficulty <u>walking on a flat firm surface at least 200 meters without help from someone</u>? Would you say….[*Read response categories*]

Children aged x>=5 years (WG)
7) Compared with children of the same age does [he/she] have difficulty <u>walking half a km on level ground</u>, that would be the length of five football fields or five city blocks without help from someone? Would you say… [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

COMMUNICATION

Children aged 1 year<=x<2 years (UNICEF)

8) Compared with children of the same age does [he/she] have difficulty <u>naming at least one object</u> (animal, toy, cup, spoon)? Would you say….. [*Read response categories*]

Children aged 2 years<=x<3 years (GB)

9) Compared with children of the same age does [he/she] have difficulty <u>asking questions or joining 2 or more words together to make sentences</u> like 'car go' or 'mummy eat'? Would you say…[*Read response categories*]

Children aged 3 years<=x<5 years (GB)

10) Compared with children of the same age does [he/she] have difficulty <u>telling you what he has been doing or about something that has happened to him/her</u>? Would you say…. [*Read response categories*]

Children aged x>=5 years (WG)

11) Compared with children of the same age and using [his/her] usual (customary) language, does [he/she] have difficulty <u>communicating, for example understanding or being understood</u>? Would you say….. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Questions (4)

LEARNING AND APPLYING KNOWLEDGE
Children aged 1 year<=x<=5 years (UNICEF)
12) Compared with children of the same age does [he/she] have difficulty learning "to do things"? Would you say…..[*Read response categories*]

Children aged 6 years<=x<12 years (6 years<=x<9 years) (ICF-CY)
13) Compared with children of the same age does [he/she] have difficulty learning to read or to write or to calculate? Would you say…. [*Read response categories*]

Children aged x>=12 years (x>=9 years) (ICF-CY)
14) Compared with children of the same age does [he/she] have difficulty reading or writing or calculating? Would you say….. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Questions (5)

RELATIONSHIPS
Children aged x<=3 years (ICF-CY)
15) Compared with children of the same age does [he/she] have difficulty <u>relating to parents and relatives</u>? Would you say….[*Read response categories*]

Children aged 4 years<=x<12 years (ICF-CY)
16) Compared with children of the same age does [he/she] have difficulty <u>relating to others children such as friends or classmates</u>? Would you say …..[*Read response categories*]

Children aged x>=13 years (ICF-CY)
17) Compared with children of the same age does [he/she] have difficulty <u>in making friends</u>? Would you say…. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Questions (5)

PLAYING

Children aged x<12 years (ICF-CY)

18) Compared with children of the same age does [he/she] have difficulty playing alone or with others?   Would you say…. [*Read response categories*]

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all / Unable to do
7) Don't know
9) Refused

Challenges (1)

The work group is aware that the set of questions proposed is only a starting point for the future work and that for some crucial issues it is necessary a further discussion in order to proceed in the work.

1) Reference age of population surveyed

As mentioned before, the reference age for this set of questions is 0-17 years; nevertheless the inclusion of children of 0-2 aged could be subject to new debate as it represents a range age in which the development process is very subjective and culturally influenced, and any delay is often not a symptom of limitation. A similar problem can be observed also for the age group 3-5.

The choices at this point would be:
a) to maintain the reference age as it is and take this into account when defining the criteria for determining the population at risk,
b) to change the age range of the reference population from 0-17 to 2-17 or 5-17.

Challenges (2)

2) Age Threshold

Since many questions are age specific we need to identify a suitable age range in order to avoid, as far as possible, to count children who are in only slow-growing development instead of in a long-term situation.

This first draft version of questions has been brought to the attention of an Italian paediatrician who suggested, in some cases, different age range that have been reported in parentheses. The choice should be done according with the different cultural experience and taking also into account the opinion of other paediatricians.

Moreover different age groups in different questions can arise problems with the interviewer.

Challenges (3)

3) Use of culturally equivalent examples in the questions

There are advantages and disadvantages to giving examples in questions. Some argue that it adds specificity, so less prone to ambiguity; others argue that it limits the focus, i.e. respondents only think of the examples given and not the general category referred to by the examples. If examples are given then they must be universal. Using culturally equivalent examples could be dangerous.

4) Mobility domain

The difficulty in the mobility area could be measured in terms not only of *distance* but also in terms of *time* spend to do a single activity. The group will take into account if it is better for the respondents to refer to distance or to time.

Comments and suggestions

Thank you!!!!!

Criteria

The criteria were selected according to the Recommendation of the Commission of the European Communities on the independence, integrity and accountability of the national Community statistical authorities.

Relevance: the information meet the needs of users;

Accuracy: the information collected is accurate;

Reliability: the information provide a reliably portray reality;

Coherence and comparability: the information is consistent internally and comparable among regions and countries;

Clarity: the information is clear and understandable;

Validity: there is consensus on the part of users and experts that the indicator is related to the dimension it is supposed to assess and cover the whole dimension it is supposed to assess, it is related to other information measuring the same dimension and it has a predictive power.